



# *Lyme Disease Association, Inc.*

PO Box 1438, Jackson, New Jersey 08527  
888-366-6611 [Lymeliter@aol.com](mailto:Lymeliter@aol.com) 732-938-7215 (Fax)  
[LymeDiseaseAssociation.org](http://LymeDiseaseAssociation.org)

LDA Connecticut Charity Registration # 10368

## **LDA CONNECTICUT PARTNERS**

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### **Testimony before the Connecticut Public Health Committee February 26, 2007**

#### **Madam Chairwoman and Committee Members,**

Thank you for the opportunity to testify on this very important piece of Lyme disease legislation, Bill 5747 (Bartlett).

Since Connecticut's 2003 removal of mandatory lab reporting, Lyme disease reported case numbers have reflected a paper drop<sup>1</sup> which is dangerous to Connecticut residents. A drop in numbers translates into decreased awareness which often leads to a delayed diagnosis. According to an actuarial study in the journal **Contingencies** on Lyme disease costs, "37% of the financial costs of this disease is incurred before the correct diagnosis is made."<sup>2</sup>

A delay in diagnosis also leads to more chronic disease since the Lyme bacterium can get into the brain within 24 hours of a tick bite.<sup>3</sup> Chronic Lyme is more costly to patients physically, mentally, and financially. According to a 1998 study in a CDC journal, early Lyme costs\* averaged \$161 per patient and neurologic longstanding Lyme disease averaged \$61,243.<sup>4</sup> Chronic Lyme is also more costly to the state and federal government in terms of disability and other costs such as those incurred by school districts for impacted areas such special services, home instruction, substitute teachers.<sup>5</sup>

Statistics drive our society, and a perceived decrease in Lyme disease cases may also result in public complacency and lack of precautions. This complacency results in a higher disease incidence. According to the CDC, Lyme disease is most common in boys ages 5-19 and combined boys & girls ages 5-9.<sup>6</sup> That lack of awareness has the greatest impact on our most vulnerable resource, our children.

According to a CDC study of 65 children with Lyme disease in grades K-12 in a 5 township area of Monmouth & Ocean Counties in New Jersey, the median number of school days missed was 140, with median duration of home instruction, 153 days. 78% of parents said their children experienced a fall in grade point average during the time of illness. 78.6% experienced a decrease in friends. "...often, patients spent large blocks of time as semi-invalids, isolated from social groups and missing out on cultural, sports and social activities....School performance of nearly all patients fell sometimes drastically, and in several instances, was said to interfere with selection by colleges and universities."<sup>7</sup> A study at Columbia University demonstrated a drop in 22 points in IQ of a student with Lyme disease, later reversed with treatment.<sup>8</sup>

Case numbers drive awareness and lessen public complacency. Without mandatory lab reporting, Connecticut's reported cases over three years, from 2003-05, totaled 4,561. That total number is lower than total number of reported cases for the single year 2002, the last year lab reporting was mandatory-4,631 reported cases.<sup>9</sup>

Disease funding is often predicated on case numbers. The plunge in Connecticut reported cases played a significant role in the nationwide case decline in 2004.<sup>10</sup> In 2004, the federal government expended \$33.6 million total on Lyme disease. In 2005, the government figure dropped 3% to \$32.6 million,<sup>11</sup> in an area already vastly under funded. It does not help that reported case numbers are only 10% of actual case numbers<sup>12</sup> meeting the CDC surveillance criteria and that no one tracks cases that do not meet the CDC surveillance criteria.

Connecticut and Rhode Island numbers were artificially lower in 2005. Rhode Island had made some internal changes to its reporting system effective in 2005<sup>13</sup> but quickly understood the negative significance of its reporting changes and promptly rectified its methods.\*\* Its reported numbers are again justifiably on the rise. California instituted mandatory lab reporting of Lyme disease in September 2005, and its case numbers went from 32 cases in 2004 to 174 cases in 2006.<sup>14</sup>

Facts support the reinstatement of mandatory lab reporting which should be implemented in conjunction with a two-tier reporting system for Lyme disease. LDA made this recommendation as a member of the Connecticut Lyme Disease Coalition to Commissioner Galvin and the Attorney General in an April 2004 private meeting. Currently, all cases are initially accepted and screened and those meeting the surveillance criteria are sent to the CDC for surveillance purposes. Other cases not meeting surveillance criteria are discarded. The two-tier system would require a subsequent step, the now discarded cases would be filed in a separate tier as physician diagnosed, non-surveillance cases.

Benefits are that doctors would be more inclined to spend the time and money to report cases, thus there would be better tracking of cases; doctors would be more willing to diagnose and treat knowing their clinical diagnoses are accepted and not looked upon with suspicion; there would be a more widespread acceptance that the surveillance criteria are not diagnostic tools; and less chronic disease would result. If this were implemented along with reinstated mandatory lab reporting, Connecticut would have the most effective tracking system in the country for Lyme disease cases. Thank you.

## Endnotes

<sup>1</sup> Centers for Disease Control & Prevention, *Lyme Disease Cases by State 1993-2005*  
[http://www.cdc.gov/ncidod/dvbid/lyme/resources/StateTable\\_05.pdf](http://www.cdc.gov/ncidod/dvbid/lyme/resources/StateTable_05.pdf), last reviewed Aug. 28, 2006.

<sup>2</sup> Irwin Vanderhoof, *Lyme Disease the Cost to Society*, **Contingencies** January/February 1993.

<sup>3</sup> Steere, Allen, Mandel, Douglas, and Bennett's *Principals & Practices of Infectious Diseases*, 4<sup>th</sup> ed. 1995.

<sup>4</sup> Martin I. Meltzer *The Cost Effectiveness of Vaccinating against Lyme Disease* **CDC Emerging Infectious Diseases**; Vol.5, No.3; 1999 May-June;5(3)321-8.

\* This is in 1996 costs not adjusted to 2007. The following additional significant costs to society aren't measured by this table: special education needs for children, disability, increased medical and insurance costs, and livestock losses, etc.

Also, there are personal losses: friends, employment, self, esteem, domicile, and breakup of families.

<sup>5</sup> Patricia Smith, Wall Township, NJ, Board of Education member *NJ School District Study on Impact of Lyme Disease on School Districts* presented in Washington DC Congressionally hosted meeting with CDC & NIH, March 12, 1992.

<sup>6</sup> Centers for Disease Control & Prevention *Average Annual Incidence of Reported Cases of Lyme Disease by Age Group & Sex*  
[http://www.cdc.gov/ncidod/dvbid/lyme/ld\\_MeanAnnualIncidence.htm](http://www.cdc.gov/ncidod/dvbid/lyme/ld_MeanAnnualIncidence.htm).

<sup>7</sup> CDC presented study in Wall Township, NJ, October 1992 at Congressional meeting. Study later published in *Lyme Times Children's Educational Issue*, ed. CALDA, Summer 2006.

<sup>8</sup> Brian Fallon MD *The Underdiagnosis of Neuropsychiatric Lyme Disease in Children & Adult*, *The psychiatric Clinics of North America*, Vol.21, No.3, Sept.1998.

<sup>9</sup> Centers for Disease Control & Prevention *Lyme Disease Cases by State 1993-2005*  
[http://www.cdc.gov/ncidod/dvbid/lyme/resources/StateTable\\_05.pdf](http://www.cdc.gov/ncidod/dvbid/lyme/resources/StateTable_05.pdf) Reported, last reviewed Aug. 28, 2006.

<sup>10</sup> Statement based on CDC figures, see endnote 1.

<sup>11</sup> Figures obtained from NIH website and from the CDC through (NJ) Congressman Christopher H. Smith's office.

<sup>12</sup> Paul Meade, Centers for Disease Control & Prevention; Jessica Adler, Lyme Disease, *NJ Herald News* 5-4-04

<sup>13</sup> LDA phone conversation with Rhode Island DOH's Dr. Bandy on several occasions including 2-23-07.

\*\* Rhode Island did not end mandatory laboratory reporting at any time.

<sup>14</sup> Department of Health Services, State of California, *California Summary Monthly Report Selected Reportable Diseases*,  
<http://www.dhs.ca.gov/ps/dcdc/pdf/cdtables/CM-SEP2006.pdf>, September 2006, Report Weeks 36-39 September 3- September 30, 2006.